Boarder Babies With AIDS in Harlem: Lessons in Applied Public Health

Since many children afflicted with AIDS are poor, it is our responsibility to ensure that they receive the medical and social care they need to live humane and civilized lives. It is our moral obligation to do so.[1]

Margaret C. Heagarty, MD
Director of Pediatrics,
Harlem Hospital Center,
1978–1999

Those who were involved in public health in the mid-1980s will remember New York City's "boarder babies with AIDS." These were children with HIV who lived unnecessarily in hospitals, boarding, as it were, because they had nowhere to go. They had been abandoned, orphaned, or removed from their parents' care because of drug use, neglect, or abuse. Now, more than 15 years later, it is worth reflecting on those troubled times and the role that one hospital-based program played by expanding beyond traditional roles to find innovative ways to effect change.

Pediatric AIDS, first described in 1983, appeared to have a uniformly high mortality rate in early childhood. A stigmatizing aura of hopelessness and fear of contagion surrounded HIV-infected children. Foster care placement, as a result, was extremely difficult, and it was made worse by the social consequences of crack, which had overwhelmed the system.

New York City had the highest rate of pediatric AIDS in the nation; the community of Harlem, in northern Manhattan, had one of the highest densities of maternal–newborn HIV infection in the city; and no hospital was more severely affected by the boarder baby crisis than Harlem Hospital Center, a Columbia University–affiliated municipal hospital in Central Harlem. Here, the number of children with AIDS doubled annually from 1983 through 1989, 3% to 5% of pregnant women were infected with HIV, and the epidemic was quickly moving from its original tight link with intravenous drug use to a more common association with heterosexual contact and use of crack cocaine.[2] Nearly 10% of babies born in Harlem went directly into foster care, primarily because of drug-related social problems; these babies were 8 times more likely to be HIV-exposed than those babies discharged to their mothers.[2]

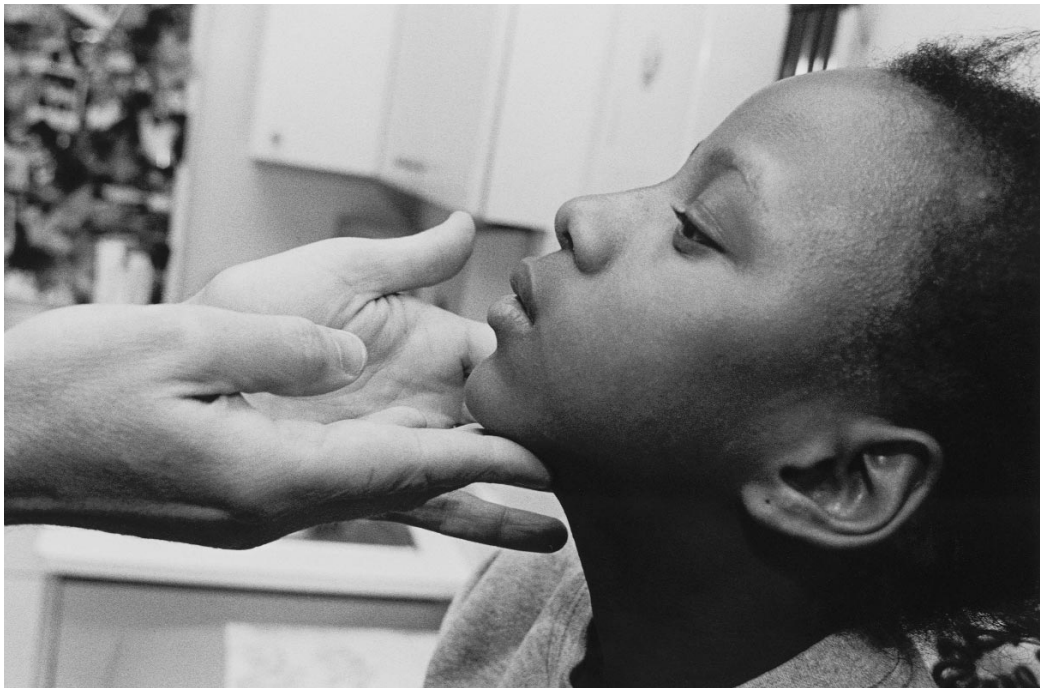
A CHALLENGE FOR TRADITIONAL APPROACHES

Though we were working "in the trenches" of a city hospital, beset by chronic underfunding and inadequate staffing, we were academic pediatricians who responded to this new epidemic boldly yet traditionally: we designed and implemented a model program to provide clinical care for families with HIV[3]; joined statewide efforts to define standards of clinical care[4]; worked with day care, foster care, and school authorities to create informed policies; studied the epidemiology of maternal–newborn HIV infection and its natural history in children[5]; participated in the first experimental therapeutic trial for HIV-infected children; and created a clinical trials unit.[6]

Boarder babies, however, presented a dilemma we were not prepared to solve. Soon, more than a dozen infants and children were housed on our wards, staying an average of 339 days; one child stayed 4 years.[7] We found ourselves confounded by what amounted to a group home on our wards, but with the rules, restrictions, risks, and aesthetics of a hospital. The cribs had cold metal frames. There were few toys. The children could not leave the hospital. Family visits were infrequent or nonexistent, and volunteers were sparse. Inadequate though it was, doctors, nurses, and other hospital staff took on surrogate parent roles, fuming with moral indignation about the inhumane predicament in which these children were caught.

OUT OF THE IVORY TOWER, INTO THE COMMUNITY

We recognized that the complexity of these children's needs would require multiple systems to work together toward a solution. Boarder babies with AIDS had no organizational intercessor, such as New York's Gay Men's Health Crisis, to press for governmental and public beneficence. But as we looked for someone else to take the lead and found everyone fenced in by traditional boundaries, we realized with reluctance that the



An 11-year-old girl is examined for enlargement of her lymph nodes at Incarnation Children's Center, New York City. Photo courtesy of Eugene Richards.

moral prerogative weighed most heavily on us, who lived every day with these children.

We began by telling the story to anyone who would listen: media, government officials, dignitaries. At the Surgeon General's Workshop on Children with HIV Infection and Their Families in 1987, we highlighted the plight of boarder babies with AIDS and asked for preventive services to keep HIV-infected children out of foster care, funding to help the foster care system recruit foster parents, and the creation of innovative community-based nurturing homes for HIV-infected children in New York City and in Newark, NJ. This last proposal met with significant opposition within child welfare circles, where the terms "Dickensian," "retrogressive," and "warehousing" were used to denounce the idea. But those who came and witnessed for themselves the pathos of the situation became advocates. Support grew for the creation of one or more group homes.

The pediatricians of Harlem Hospital Center took the lead in organizing an unlikely group of collaborators: doctors, nurses, priests, nuns, social workers, a Jewish philanthropist, and government officials. The group developed plans for New York City's first (and, as it turned out, only) group residence for children with HIV and obtained the support of the mayor and the cardinal of the Catholic Archdiocese of New York. Local churches, service organizations, police precinct councils, and community boards were asked to lend support. Plans were then submitted to and approved by city and state health and social services agencies. Thus the group obtained hard funding.

NEW YORK'S ONLY RESIDENCE FOR CHILDREN WITH HIV

Incarnation Children's Center (ICC) was created in 1988, when a 4-story red brick former convent in upper Manhattan was converted into a homelike residence for 24 HIV-positive children. Just before the center opened in March 1989, worldwide attention was focused on the plight of boarder babies with AIDS when Diana, Princess of Wales, visited Harlem Hospital Center. Her visit was widely publicized; not only did it sensitize the public to the needs of children with HIV/AIDS, but it was followed by an abrupt increase in the rate of foster parent recruitment throughout the city.

ICC began working closely with the city's 8 HIV-specialized foster care agencies, which, in response to the new surge of foster parents, opened foster homes so efficiently that the average length of stay at ICC was unexpectedly short: 1 month. During the program's first 2 years, more than 160 HIV-positive children (two thirds of New York City's AIDS boarder babies) were admitted to ICC, which was dubbed "the Ellis Island for homeless children with AIDS."

By the end of 2 years, there was a citywide surplus of foster parents for all but the sickest children with HIV. Multiple factors had coalesced to end New York City's AIDS boarder baby crisis, but ICC had played a pivotal role in this, one of New York City's least well-known success stories.

The next unmet need was clear: care for children with AIDS who were too sick to live at home but not sick enough to require hospitalization. Having learned that very ill children often improved dramatically with proper nurturing and high-quality medical and nursing care, ICC pioneered the concept of convalescent care for them. Many children presumed terminally ill improved clinically and returned to a home setting. For other children, ICC remained a sanctuary full of love in which to spend their final days.

ICC has now cared for more than 700 HIV-positive children from throughout New York City; the largest percentage have come from Harlem. Of those who have received residential care, more than 80% have been discharged to kinship or nonkinship foster homes. In the end, nearly all of them were adopted.

Over the past 5 years, mother-to-baby HIV transmission has dropped dramatically in New York City. With improved treatments for HIV, infected babies are surviving into late childhood, adolescence, and even adulthood. It appears likely that the pediatric AIDS epidemic will, over the next decade, largely disappear in the United States.

AN IRONIC TWIST TO THE STORY

In 15 years, we have repeatedly witnessed the improbable. It seemed that boarder babies with AIDS would never be freed from hospital wards, but ICC was created. Despite our doubts, a surprising number of saintlike individuals stepped forward to become foster parents and then adoptive parents. Infected babies who once seemed destined for early death now shave and go on dates. But amid all this good news lies an ironic and sad twist.

A startlingly high percentage of older children with HIV have severe behavioral problems and mental illness; some who have reached adolescence display aggressive and inappropriate sexual behaviors. Many of their biological parents are or were mentally ill, drug-addicted, and HIV-infected. Familial predisposition, together with intrauterine drug exposure and life's emotionally traumatic experiences, may account for the high rates of mental illness in HIV-infected children.[8,9]

A small but increasing number of older HIV-infected children and adolescents are being rejected by their adoptive parents. Some of these parents confide that their bravery was geared toward babies who were expected to die; they did not foresee such longevity, complexity of care needs, and uncontrollable behaviors. These children are being rejected by schools as well.

Some are in residence at ICC, which continues to play an important role as a chronic care facility. But those with severe mental illness or who act out sexually cannot safely be maintained there.

Some of these children have been shuttled between hospital psychiatric and pediatric wards, chronic care facilities, and residential treatment centers, all of which actively try to refer them elsewhere. There is no ideal setting for them. They need to be in psychiatric nursing homes, but there is no such thing. Some have ended up in the juvenile justice system, which is likely to become the next dumping ground.

And so we have a new crop of "boarder babies": older, sadder, more difficult to care for than ever. Full circle. It's time for those who have the energy to tell the story to anyone who will listen. ■

Stephen W. Nicholas, MD
Elaine J. Abrams, MD

About the Authors

The authors are with the Department of Pediatrics, College of Physicians and Surgeons, Columbia University, New York, NY. Dr Nicholas is also with the Department of Pediatrics and Dr Abrams is with the Family Care Clinic, Harlem Hospital Center, New York, NY.

Requests for reprints should be sent to Stephen W. Nicholas, MD, Harlem Hospital Center, 506 Lenox Ave, Room 17-105, New York, NY 10037 (e-mail: swn2@columbia.edu).

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